



## GIST Awareness Day

We are inspired by the Life Raft Group <https://liferaftgroup.org/> and leave no stone unturned to make this important awareness campaign also our very own year after year.

“Despite all the work done by our amazing members and friends to date there is still a huge lack of education and awareness that exists within the medical community and general public about

GIST. The ultimate goal of GIST Awareness Day is to bring so much attention to GIST that knowing what it is will no longer be so “rare”. GIST Awareness Day serves as the yearly pinnacle of our education, awareness and advocacy efforts and provides those outside the GIST community a chance to learn about and lend their support to this important cause.

**GIST Awareness Day (GAD) Events are held across the world each year on July 13th.”**



## Amma Speaks

CML & GIST - Strange Bedfellows is what would always come to my mind when I thought of the two cancers we began working with - CML & GIST.

As different as chalk is from cheese. One a rare Leukaemia and the other an even rarer Sarcoma.

But the Magic Bullet brought them together and now there's no keeping them apart. Imatinib that marvellous drug burst on the firmament of cancer treatment like no other drug before it, heralding the era of targeted therapy. Not only did it bring these two malignancies on the same platform but, thanks to the Glivec Assistance

Patient Programme it brought together patients and caregivers who were looking at a new lease of life, life with cancer by their side, together.

Friends of Max had to happen. The support group arm of The Max Foundation that was managing the Access Programme. It was meant to be.

Soon, there were thousands of CML and hundreds of GIST patients who were enrolled into the programme and under our watchful and caring eyes.

And thus began this unlikely fraternity, this brotherhood that defied any and all kinds of classification on the cancer board.

Yes, the GIST arm of the family was

small but in no way was it's voice less powerful or its presence in the group less impactful.

This issue celebrates the spirit of our GISTers as they are fondly called... acknowledges their vibrant presence in Friends of Max, their leadership skills and inspirational contribution to our growth as a support group that has redefined the very meaning of support and advocacy.

So seamless is their union with the CML fraternity that what has surfaced is a shared show of strength, courage and dignity which takes us all ahead on our journey of life with so much hope into the years ahead.

- Viji Venkatesh



## GIST Focused Meetings

The Max Foundation works with hundreds of patients who have been diagnosed with GIST. These are people who are living with this rare malignancy and who show utmost fortitude as they go about leading their lives with great courage and dignity.

The GIST arm of Friends of Max is small but their needs are many and varied.

Recognising the importance of focusing on

and addressing many of these specific requirements (a lot of them being unmet needs) Support Group Meetings for only GIST patients are held all over the country in various cities. Friends of Max is grateful to the physician community across the length and breadth of the country for giving us their invaluable support and encouragement ensuring the success of these meetings.

## Patientspeak



**Dr Nikhil Guhagarkar**

The word Amma stands for mother and that is what you have been to all of us in FOM.

FOM has been like a family thanks to all the warmth, smiles and hugs we experience when we all meet.

It is so energizing and empowering to meet you, the Max team and fellow members. Everyone has a smile and something positive to share, there is so much concern about each other's wellbeing it is touching.

This beautiful connection between previous strangers going on to become a warm connect is amazing and rare as it is a bond between people who are previously not family or friends but commandos on a mission to wipe out a disease.

The camaraderie which exists between the members is amazing at the drop of the hat we can be with each other like Pranay coming down to Mumbai just for a concert to be with his friends or my going to Pranay's rock concert CFC Adda is a tribute to the beautiful warm network Amma you, your Max team and all the members across India have formed.

Bharatji from Delhi makes it a point to come for the Mumbai meetings, Pranay and Nandini come to Mumbai from Hyderabad for the same, Gafoor Bhai and others travel from far to be present for the meeting.

It is very encouraging to meet positive people like the Shukla family, Rashmi, George, Ganpat, and many others.

Thanks to the dedicated team of doctors who selflessly dedicate their time to be part of the meetings and patiently answer each question in the local language.

Thank you FOM for printing patient education booklet on 'Holistic living'!

It has been an honour to represent FOM at the New Horizons GIST Annual Conferences and SPAEN Annual Conferences.

Was a special honour for Viji to receive the

International award for FOM in USA 2017, I felt humbled to receive the Advocacy in Action Award from SPAEN in Milan 2018.

Though we received these awards, it was on behalf of all in FOM and all the selfless work that every member has put in to make FOM so special.

Truly FOM is a unique organization and I'm proud to be part of it.



**Vasmvada Shukla**

My tryst with GIST began in 1999. I underwent a surgery for excision of a tumor which then recurred in 2000 and I had to undergo a repeat surgery in 2000. In 2001, I was advised to start Glivec. We purchased the medication for a few months initially but eventually exhausted our resources.

It was then that the GIPAP and The Max Foundation came as God sent angels for me. I was the first GIST patient to be included in the GIPAP program. I have since been a beneficiary of the program and have been receiving the medication through GIPAP.

I am very thankful to Novartis, Viji and The Max Foundation for all the assistance that I have received through the program. It is 18 years now since my starting the medication and I continue to enjoy good health thanks to Glivec.

I pray to God that that they continue the good work and keep on reaching out to patients in need and help them in the fight to overcome this disease.



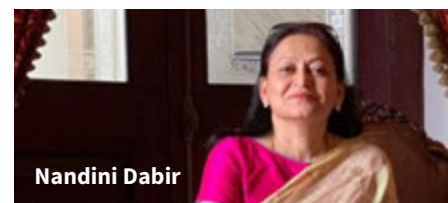
**Pranay Ranjan**

All of us GISTers are Friends Forever, and FOM has been that glue, keeping us all bonded together. Thanks to this group that we are more humble and also more hopeful, than ever!



**George Colaco**

Every one of us GISTERS are as one family and FOM is a platform for us to share and be together with each other in good and bad times. Viji Amma and her team at The Max Foundation are the Pillars of FOM to hold us under one roof. My thanks to FOM GISTERS GROUP.



**Nandini Dabir**

FOM and The Max Foundation, Viji and her team are an integral part of every GISTer's life here. I would like to express my gratitude to this amazing group for all the support and guidance we receive from them.



**Rashmi Sachade**

We all GISTers are traveling in the same boat. And the captain of our boat is my all time favorite, my inspiration, respectable, lovable Viji Maa.. Team of Max is like my family. Whenever we need they are always there. I love to express my respect and love towards one and all in FOM.

**Get more GIST related information on our website :**

<http://friendsofmax.info/home/category/fom-gisters/>

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## GIST Disease Overview

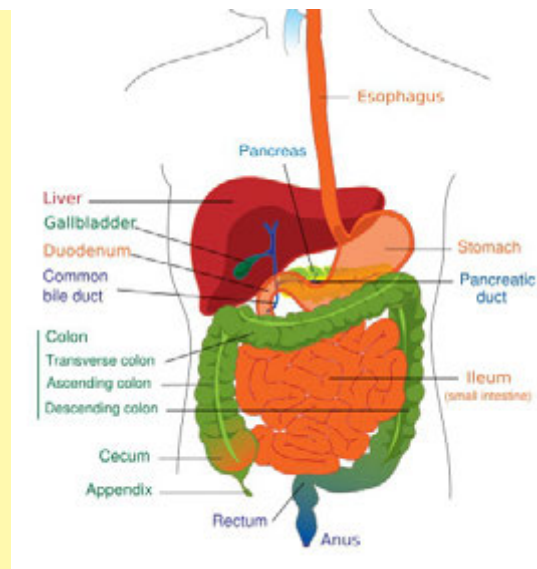
Gastrointestinal stromal tumor (GIST) is a rare cancer affecting the digestive tract or nearby structures within the abdomen. GI stromal tumor, or GIST cancer, is a sarcoma. Sarcomas are cancers that grow from cells of the body's connective or supportive tissues such as bone, cartilage, tendons, nerves, fat, muscle, synovial tissue (tissue around joints), or blood vessels. (Most cancers are carcinomas, not sarcomas.)

Gastrointestinal stromal tumor (GIST) is quite rare. Most cancers are carcinomas, meaning that they derive from cells in the skin (or epithelium), either our outer-body skin or the skin-like lining of our internal body cavities and the digestive or gastrointestinal (GI) tract. Most GI tract cancers are carcinomas, such as those commonly known as stomach cancer,

colon cancer, etc.

GIST is not related to these common GI cancers; it is a sarcoma. Of all adult cancers, sarcomas represent about 1%. GIST is one of the more common of about 50 types of sarcoma. Primary tumors are in the original site of development, before any spread to other locations.

Primary gastrointestinal stromal tumors (GIST cancers) may occur anywhere along the gastrointestinal tract from the esophagus to the anus. The most frequent site for GISTs is the stomach (about 55%), followed by the duodenum and small intestine (about 30%), esophagus (about 5%), rectum (about 5%), colon (about 2%), and rare other locations. There are no known environmental or behavioural risk factors

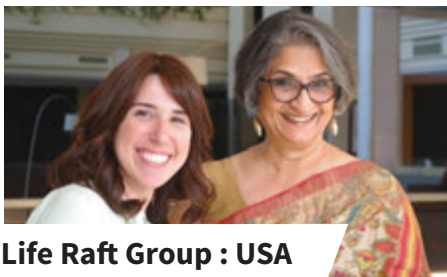


contributing to GIST. Therefore, patients should not worry that their diet or lifestyle choices contributed to GIST. Random genetic mutations are the apparent cause of GISTs

Source: <https://www.gistsupport.org/about-gist-support-international/>

## Our Regional and International Partners

What it means to be associated with FOM and why such a collaboration is so important



### Life Raft Group : USA

Collaborating is the key to success for patient advocacy groups. Patients need vital information to make informed decisions about their treatment, and groups like Friends of Max and The Life Raft Group (LRG) work fiercely to provide that information in a timely way. "It has been a pleasure to partner with Friends of Max for many years

as they have been an active participant in our GIST Awareness Day campaigns. The level of passion and personalization that they provide their patients is an inspiration!" – Piga Fernández, LRG Global Coordinator, and the Executive Director of Fundación GIST Chile

"Friends of Max are true global leaders when it comes to advocating and supporting cancer patients. We are in awe of their work with health authorities as well as contribution to sharing best practices with the global community. We look forward to continuing to collaborate with them in the future." – Sara Rothschild, LRG Senior Vice President of Program Services



### V Care : India

Friends of Max helps build a close knit, multiple stakeholder community that enables us as patient groups to collectively leverage our existing resources so patients with GIST receive the care and support, they need. V Care Foundation has been associated with Friends of Max for over a decade and appreciates the joint value that can be brought to patients as they battle a rare cancer like GIST. The lovely team at Friends of Max truly represents friends for patients, doctors and NGOs.

Vandana Gupta Founder V Care



### SPAEN : Germany

Our – Sarcoma Patients EuroNet's – objective is to change the situation for GIST patients. But this is something we need to do together and united – not as a single person, not only as one country, but globally. Especially since GIST is such a rare disease.

This is one of the things we learnt from our

collaboration with FOM: Sarcoma Patients EuroNet (SPAEN) was originally founded as European organization. FOM became one of the first members of our organization the minute we made SPAEN international. We learned that it's not enough to concentrate on Europe, but that we'd need to look after GIST patients in other countries as well.

Photo credit -Uli Deck

The collaboration with FOM as our member group is of utmost importance to us: It shows us where obstacles are and how the situation for GIST patients differs from country to country, from healthcare system to healthcare system – and what we can actually do together to change the situation for all GIST patients.

FOM does a wonderful work in India for GIST patients. We are therefore very proud that Dr. Nikhil Guhagarkar has decided to join the SPAEN board of directors in 2016 – to represent India and to drive change in GIST forward, not just nationally, but also internationally.

FOM: Thank you for your commitment and all the work you do for GIST patients in India and beyond!

Kathrin Schuster, Communications for SPAEN

## Doctorspeak

### Dr. P. Jagannath

Chairman, Dept. of Surgical Oncology  
Lilavati Hospital & Research Centre



A middle aged lady had pain in abdomen and underwent upper GI Endoscopy and was found to have GIST which is typically recognized on endoscopy and by CT Scan. She was started on Imatinib which is the treatment of choice when there is c-kit mutation in the tumour. She came back in about 3 months time and Scan now showed good response with reduction in size.

However, she had a lot of questions - 'my skin colour has changed'.

Her daughter chipped in saying 'she has become more irritable, has mood swings and also spells of giddiness'.

GIST (Gastrointestinal Stromal Tumour) is a unique tumor, most common site being stomach 48%, then small bowel 18%, duodenum 15% and others. It is also a unique tumour because it is the first solid tumour in which a mutation in receptor c-kit is recognized and is blocked by the wonder drug 'Imatinib'.

Imatinib has few side effects but not severe. Imatinib is given for long periods of time before and after surgery, even for 5 years. Though the side effects are not severe, they are there, like muscle cramps, bit of nausea, swelling of feet and a couple of my patients have complained of loss of appetite.

As it is a long term treatment it is very important that patients not only understand the side effects but also learn how to cope with that. The fact is that most of the time the doctors in India are busy and the pharma industry may not be reachable so it

becomes very necessary to have a support group. The biggest benefit of the support group is not just to bring the community together but also exchange notes and anticipate side effects. It is always good for a patient to hear from another patient as to how they cope with the symptoms.

Friends of Max Support group is a phenomenal group. I know many of my patients who are part of the group. Some of them like Dr. Nikhil Guhagarkar have been so active that they attend all international meetings and are up to date with clinical information which would be of great help to other patients. In fact, I had a chance to refer many patients to Dr. Guhagarkar as his network of doctor experts dealing with GIST is substantial and has benefitted a lot of patients. In all, Friends of Max GIST support group is an excellent example of patient support group, coordinated well for the benefit of patient and also healthcare community as many of their issues are sorted out.

## Guidelines for Nutrition in GIST

1. Eat Natural and if possible have Organic (chemical free) food.
2. Have a Diet which is HIGH in fibre, fruits and vegetables and LOW in red and processed meat, saturated fat (fatty meats, biscuits, cheese and butter) and salt. Fibre comes from the outer layer of grains, fruits, vegetables, legumes and nuts. Fibre helps in adding bulk to our stools and moves food quickly through the digestive system. This eliminates accumulated toxins, fats and waste from the body.
3. Have at least five portions of fruits and vegetables everyday. A portion of fruit is equal to a middle size apple or banana. A portion of vegetable is three heaped tablespoons of cooked vegetables or a bowl of salad. Have local, fresh and seasonal fruits and vegetables instead of those which have travelled thousands of kilometres to reach your table.
4. Avoid packaged / processed foods on daily basis like chips/noodles / aerated cola drinks / bakery products. All processed / packaged foods have preservatives / chemicals/ excess of salt to enhance their shelf life. These are harmful to our system.
5. Avoid processed meats like sausages / hotdogs / salami / ham / bacon and other meats which are factory processed. These are known to have a lot of chemicals and hormones which when consumed on regular basis do cause harm to the system. WHO has classified 'processed red meat' as Carcinogenic, i.e. it has ability to cause cancer.
6. Go easy on Oil.

### Nutritional and Holistic Tips from Patients

#### 1. Mrs N, Age 46 years

- Imatinib may cause hypocalcaemia and hence calcium rich food should be consumed along with vitamin D supplements. I take greens and broccoli, twice a week.
- I also take a cupful of nuts everyday like cashew, almonds, pine nuts, walnut and a cup of dal/lentils for protein.
- I am on Sunitinib and this drug causes severe acid reflux. So, I have stopped drinking coffee or tea in the morning and I supplement it with ABC juice i.e. apple, beetroot and carrot juice.



- I eat bland food with less salt and spice to avoid mouth sores. I drink tender coconut water every day which is rich in nutrients.
- #### 2. Mr P, Age 48 years
- I strongly believe that Yoga and Meditation should be practiced daily. Yoga helps in fine tuning the body and shaping and strengthening the muscles tissues and meditation helps in shaping and strengthening our brain and mind, and would refer this as mental therapeutic approach and this has healed me.

For private circulation only

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**To Donate:**

Cheques should be drawn in favour of Friends of Max and couriered to our office in Worli (Mumbai); To donate online visit [www.friendsofmax.info](http://www.friendsofmax.info); Receipts u/s 80 G of Income Tax Act, 1961 will be issued.

Friends of Max is registered as a Public Charitable Trust: Regn No E-24284(B) Mumbai, dated 4-7-2007